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Abstract

Through the 1980s and early 1990s, the course of American health research was increasingly shaped by politically aggressive activism for two particular diseases, breast cancer and AIDS (Acquired Immunodeficiency Syndrome). Even as national stakes rose, both in dollars spent and growing demands on the medical system, breast cancer and AIDS advocates made government policy-making for research ever more public and controversial. Through skillful cultivation of political strength, interest groups transformed individual health problems into collective demands, winning notable policy influence in federal agencies such as the National Institutes of Health (NIH) and Food and Drug Administration (FDA). Activists directly challenged fundamental principles of both government and medical systems, fighting to affect distribution of research funds and questioning well-established scientific methods and professional values. In the contest for decision-making power, those players achieved remarkable success in influencing and infiltrating (some critics said, undermining) both the politics and science of medical research. Between 1990 and 1995, federal appropriations for breast cancer study rose from \$90 million to \$465 million, while in that same period, NIH AIDS research rose from \$743.53 million to \$1.338 billion.

Disciplines

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Comments

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Diseases Chasing Money and Power: Breast Cancer and Aids Activism Chal- lenging Authority

Through the 1980s and early 1990s, the course of American health research was increasingly shaped by politically-aggressive activism for two particular diseases, breast cancer and AIDS (Acquired Immunodeficiency Syndrome). Even as national stakes rose, both in dollars spent and growing demands on the medical system, breast cancer and AIDS advocates made government policy-making for research ever more public and controversial. Through skillful cultivation of political strength, interest groups transformed individual health problems into collective demands, winning notable policy influence in federal agencies such as the National Institutes of Health (NIH) and Food and Drug Administration (FDA). Activists directly challenged fundamental principles of both government and medical systems, fighting to affect distribution of research funds and questioning well-established scientific methods and professional values. In the contest for decision-making power, those players achieved remarkable success in influencing and infiltrating (some critics said, undermining) both the politics and science of medical research. Between 1990 and 1995, federal appropriations for breast cancer study rose from \$90 million to \$465 million, while in that same period, NIH AIDS research rose from \$743.53 million to \$1.338 billion.¹

Twentieth-century American medicine had never been separate from politics, as demonstrated in history of cancer research.² More than simply extending the old politics of medicine, however, activists' pressure reached a new level of politicization in the last fifteen years. In previous decades, procedures for drug approval and research funding had not commonly elicited detailed public interest or sustained passion. Breast cancer and AIDS activism established FDA and NIH policy as regular topics for media analysis and high-profile public protest. Through activism, policy-

making "insiders" (officials and researchers whose claims to expertise were secured by professional acknowledgement) were forced to cede some territory to "outsiders." Breast cancer and AIDS movements affected direction of funding and helped re-write official guidelines for research, testing, and drug approval, even as some scientists complained such changes endangered medical progress. Men and women without specialized education or research credentials found a decision-making place alongside scientists and agency executives. Such a development could not be taken for granted; in the same years, for example, the National Science Foundation was not subject to any parallel public activism which succeeded in pushing broad policy change.

Challenging medical and agency authority was fundamental to AIDS and breast cancer activism, both as a philosophical commitment and as means for turning frustration over lack of medical advance into political mobilization. Activists operated on the assumption that research was primarily driven not by intellectual curiosity, but by the political climate, which could then be manipulated. They approached science and medicine not as disciplines of expertise to be judged on their own professional terms, but as potentially (if not actually) flawed social and political enterprises. Though scientific and medical workers themselves tended to value research as almost ideal objective analysis, activists accused researchers and federal officials of incompetence and unfairness, if not gender bias, racism, and homophobia. In sometimes conspiratorial-sounding language blaming "the system" for literally playing with lives, activists defined research as fair game for public confrontation. Surgeon/activist Susan Love likened the battle for breast cancer funds to past fights over "civil rights and war resistance and the early women's movement," while some AIDS activists adopted Malcolm X's slogan, "By any means necessary."

While observers in recent years have written volumes on breast cancer and AIDS separately, their policy-making significance for the 1980s and early 1990s can be best appreciated by examining them in tandem. Their activism evolved with significant parallels; not coincidentally, since the two causes learned from each other's approaches and cooperated. For both breast cancer and AIDS, activism coalesced around specific population and political subgroups: women and homosexuals respectively; though sexual orientation did not limit AIDS infection, gay groups took leadership in promoting action. In each case, mobilization, protest, and hard-fought campaigns brought public attention and political clout to disease-specific concern, winning activists recognition and policy concessions even as they questioned scientific and government authority.

Politicization of Women's Health

1980s and early 1990s politicization of breast cancer was closely linked to general history of modern feminist concerns. Through the 1960s, as women organized around explicitly feminist motivations, they began scrutinizing gender dimensions of political, social and economic life, including health care. Under the maxim of "the personal as political," women's health was transformed from individual problems into a mutual concern and impetus for political action.

From its 1969 start, the Boston Women's Health Collective encouraged women to educate themselves about their physical well-being, to become informed health consumers who would refuse to tolerate condescending or inadequate treatment by the medical system. The group's 1974 reference *Our Bodies, Ourselves* described both medical details and women's own health experiences, from childbirth to contraception and more; within a decade, the text sold more than two million copies nationwide. In 1975, concerned parties established the National Women's Health Network to draw attention to female health issues and distribute information. Female-friendly health clinics became important providers of women's medical treatment and also worked to influence policy: rather than waiting for development of new contraceptives, feminist clinics helped promote cervical cap research.⁴

Women's health mobilization also crystallized in response to two medical disasters: the Dalkon Shield, touted as a wonderful new 1970s IUD, turned out to cause miscarriage and pelvic inflammatory disease (some severe cases proving fatal), while the drug DES, once popularly administered to pregnant women in hope of avoiding miscarriage, was linked to cancer and reproductive problems extending even two generations down from users.⁵ Frustrated by seeming failure of doctors, lawyers, and politicians to provide information, health care, or compensation, concerned women formed grass-roots organizations such as DES Action to support affected women, raise public awareness, and maintain political, medical, and legal pressure.

By the late 1980s, feminist advocates argued that beyond disastrous products such as DES and the Shield, women's health had been systematically endangered by an entire medical establishment. Health was a gendered issue, critics contended; despite evidence of important medical differences between men and women on such matters as cholesterol levels, researchers often investigated health questions or tested new drugs on male subjects alone. The multi-year Physician's Health Study espe-

cially troubled women's advocates; the report relied on an all-male sample of 22,000 doctors and so offered no evidence whether aspirin's cardiovascular benefits held true for females. The project head pointed to inherent constraints such as relative scarcity of older female doctors to complement the male study population, though critics asked why researchers could not draw on nurses or other predominantly female groups. The director maintained female subjects would also have confused results and increased expense of an already difficult project by introducing new scientific factors such as hormonal interactions, a fairly common attitude among researchers. He warned science would suffer if political pressure compelled researchers to alter studies, regardless of appropriateness, to fit a mandated gender balance; drug companies added their own cautions that potential harm to a fetus meant special risk in testing women of childbearing age.⁶

Nevertheless, political forces had acquired momentum. In 1986, Public Health Service (PHS) officials spoke up for greater awareness of women's issues in medical studies, NIH then created policy encouraging all grant applicants to "consider the inclusion of women" and justify any research excluding female subjects. Four years later, however, a General Accounting Office (GAO) analysis confirmed women's suspicions that the new policy had been ineffective, that numerous research proposals still ignored gender considerations. The Congressional Caucus for Women's Issues subsequently introduced Women's Health Equity Act legislation which would, among other measures, create a special OB/GYN program at NIH and enforce rules for including female subjects in research. The Act drew growing attention, and soon House and Senate subcommittees adopted some of its provisions as part of NIH reauthorization. To try regaining credibility and demonstrate good faith on the question of women and research, NIH officials adopted strategy to separate and institutionalize responsibility for female health. In September, 1990, NIH established a new Office of Research on Women's Health, winning praise from Women's Caucus co-chair, Representative Patricia Schroeder, who had previously blamed male-dominated policy for leaving women's health "at risk."⁷

The campaign for women's health united feminist advocates, sympathetic politicians such as Schroeder; individual doctors, scientists and medical researchers also supported the cause and organized groups such as the Society for the Advancement of Women's Health Research. By the 1990s, medical journals featured notable numbers of articles and editorials on the issue, as JAMA put it, whether there was "still too much extrapolation from data on middle-aged white men."⁸

Interest groups made an ever-larger case, arguing that beyond women's underrepresentation in studies, gender bias extended to systematic inequity in federal health funds. For activists, dollars defined commitment; critics complained NIH committed just \$778 million to female-specific research within a \$6 billion overall budget.⁹ The National Women's Health Network pressured politicians to rectify past injustice by immediately investing more money in female medicine.

In 1991, one week after confirmation as first female head of NIH, Bernadine Healy announced the agency was creating a \$600 million, fifteen-year Women's Health Initiative to redress history of gendered research imbalance. Healy called this NIH's "awakening to a simple fact... that women have unique medical problems." Explaining that women at or past menopause had been doubly-neglected due to age as well as gender bias, the agency announced plans to concentrate on advancing medical knowledge of older women. As *Science* noted, that choice of focus also did credit to "Healy's political acumen," diverting attention from controversial reproductive topics "such as post-conception... birth control and fetal tissue transplant research."¹⁰

Healy's announcement, making national news, won approval from women's groups, while NIH reported being flooded by letters and calls expressing "enormous" interest in the new program and praise. The head of NIH's Office of Research on Women's Health commented, "Women's health has risen to the public's consciousness in a way I would not have dreamed...."¹¹ The Initiative program confirmed the 1980s-1990s transformation of medicine into a gendered policy issue, granting seemingly unquestionable political victory for activists' case that women's health deserved special attention. Initiative research, planned to involve up to 160,000 women, would represent the biggest single clinical trial and research effort in NIH history.

While gratifying women's health activists, that fact met more dubious response from some scientific and medical quarters. The Initiative's giant scale and proposed structure drew criticism: with previous NIH work centering on relatively small-scale investigations proposed by researchers, why should the agency suddenly switch to an enormous undertaking directed top-down? Even while acknowledging that women's medical problems deserved increased support than in previous years, some observers worried the new commitment represented too much too soon, that a sudden financial influx might not be the wisest means of correcting past inequity.

Other researchers expressed concern about initial scientific details, such as plans for overlapping clinical trials on 63,000 women to see how nutri-

ent supplements, exercise, low-fat food regimens, and hormone treatment affected cancer, heart disease, and osteoporosis. Several dozen female epidemiologists worried such a complicated project would be undermined by both technical flaws (sorting out multiple factors) and practical difficulties (unlikelihood of convincing women to continue demanding lifestyle changes over ten or more years of study). In 1993, a formal Institute of Medicine review criticized the Initiative on numerous grounds, though members felt "frustrated with the assignment of assessing an expensive project... already under way." Plans for investigating whether reduced-fat diets could lower breast cancer risk seemed "weakest," unlikely to yield valuable information. The committee also worried NIH had understated trial expenses, allocating under half what could be projected from cost of previous studies. The group recommended that "better designed, smaller, more focused studies" would offer "greater chance of success and probably be less costly" than one huge effort. At the same time, reviewers conceded political reality: canceling the Initiative would be seen to "prove that the government does not really care about women's health." However valid the scientific criticism, the large Initiative satisfied NIH's political needs, addressing feminist demands for funding and research attention.¹²

Focus on Breast Cancer

Within this context of activism for general women's health research, one particular disease, breast cancer, attracted increasing attention in the 1980s. New organizations were founded to focus public awareness and support concerned women; for example, the Susan G. Komen Breast Cancer Foundation, established in 1982, became known for organizing "Race for the Cure" runs in fifty-eight cities to raise money for research, education, and screening programs. Such groups gathered political strength, mobilizing to get government and public alike to recognize breast cancer as a unique concern and allocate special funds to fight the disease.

In this new political battle for breast cancer research, Susan Love, UCLA Associate Professor of Clinical Surgery and Director of the Revlon/UCLA Breast Center, established visibility and a dual identity as both doctor and political player. Historically, other practitioners, from occupational medicine pioneer Alice Hamilton to pediatrician Benjamin Spock, had combined professionalism with social and political expression. However, Love increasingly defined her medical and activist breast cancer work as inseparable, even as many health professionals still felt

uncomfortable positioning themselves to challenge the political and medical order. Love linked her political awakening to her promotion of her 1990 reference book for women concerned about breast cancer; after she tossed off a line proposing a "march topless on the White House" to "make President Bush wake up and do something about breast cancer," she found female listeners ready to take her seriously. Calling this group "fed up... that this virtual epidemic was being ignored,"¹³ Love became increasingly vocal about breast cancer being as much a political as medical battle.

Following broader campaigns for women's health research, breast cancer concerns maintained that government and medical authorities had ignored the disease even as it approached epidemic proportion; news commentator Cokie Roberts observed that women's 44,500 breast cancer deaths in 1991 exceeded the total of American soldiers killed in Vietnam.¹⁴ Activists based their work on certain presumptions: without increased federal support, the country would make little progress on breast cancer, but given satisfactory resources, movement leaders promised, the disease could be conquered so modern women's daughters and granddaughters would not experience similar fear of breast cancer. To drive this agenda, Love helped establish the National Breast Cancer Coalition in 1991, linking separate advocacy groups to multiply their political effectiveness and muster parade rallies and other demonstrations of public support. Collecting thousands of signatures in petition drives to the President and Congress demanding more breast cancer research, the Coalition gained access to present its case to both Bill and Hillary Clinton.¹⁵

Women's push for breast cancer money broke through partisan lines; Republicans such as Marilyn Quayle and Olympia Snowe joined Democrats Mary Rose Oakar and Schroeder. Senators such as Edward Kennedy and Tom Harkin (who lost several relatives to the disease) proved useful allies in Congress. Breast cancer groups also benefitted because their appeal coincided with a unique point in national politics; the 1991 nationally-televised hearings on sexual harassment charges in Clarence Thomas' confirmation as Supreme Court justice had left some Americans with an impression of Congress as insensitive to females' concerns. To mend political fences, some representatives turned to breast cancer funding to demonstrate willingness to listen to women's demands; Senator Arlen Specter, whose image had been especially damaged by harsh cross-examination of Anita Hill, especially highlighted his commitment to fighting breast cancer. Furthermore, in 1992, ongoing fallout over the hearings swept a number of women candidates into Congress; "the Anita Hill class" then established greater female representation on committees and subcommittees where they could speak up for women's health issues such as breast cancer.

As another advantage, no other advocates of specific women's diseases had achieved similarly high political profile by the 1990s, so breast cancer activists did not have to compete with other feminists for money and political consideration. Breast cancer could also be considered politically safe: while a campaign against women's lung cancer would have forced politicians to risk alienating Southern tobacco interests and defy the notoriously tough cigarette lobby, breast cancer did not seem to necessitate major confrontation. As Love acknowledged, advocates had demographics on their side; breast cancer had an image of affecting middle or upper-class Caucasian females, a crucial political constituency. For those reasons, supporting higher breast cancer funding became a way for politicians to exhibit awareness of women's issues. In 1991, government money for studying breast cancer rose \$43 million, raising by half the previous level of \$90 million; in 1992, funds soared to more than \$400 million across various federal agencies. Within the National Cancer Institute (NCI) alone, breast cancer support jumped from \$197 million to almost \$263 million between 1993 and 1994; to place that in perspective, NCI devoted just over \$90 million to lung cancer and under \$50 million to prostate cancer in that same period.¹⁶

Such developments reflected new reality: breast cancer had been established as *the* single most politically compelling part of women's medicine. In fact, politicians and advocates alike often equated feminist health concern with breast cancer issues, a powerful link. Corporate sponsors such as Revlon enlisted in fighting breast cancer, providing research funds and other resources while highlighting their support as showing the female market they took women's issues seriously. Public commitment to breast cancer research became a "safe" yet powerful symbol of sensitivity.

Such a development contrasted sharply with previous American attitudes toward breast cancer; women affected in the early twentieth century had tended to keep the disease a close secret, afraid cancer reflected badly on them personally or simply considering it a private concern. The 1980s-1990s establishment of breast cancer as a public political issue was exemplified by a sign at one rally: "Ask me about our demands to the US Govt." With ability and motivation to translate individual experience into group mobilization, transform concern into "demands," women's activists gave breast cancer new visibility and power to influence government funding decisions.

Politicization of AIDS

Just as feminist organizations provided both philosophical and practical impetus for activists to demand increasing funding and attention for

women's health in general and breast cancer in particular, so AIDS activism reflected mobilization of American's gay community. While the 1960s and 1970s had represented an alternately heady and frustrating period of personal concern and political organization for gays, the 1980s brought what seemed the greatest challenge yet, a devastating and mysterious new disease. By 1981, West Coast doctors treating the gay population started noticing clusters of immune deficiency problems. Physicians and researchers at the Centers for Disease Control (CDC) found unusually frequent reports of rare pneumonia and cancer forms. CDC medical detectives initially had to sort through a variety of possible causes, from chemical poisoning to recreational drug use, and perceived the threat as sufficiently urgent to warrant special studies of what some referred to as "Gay-Related Immune Deficiency" (GRID). However, Reagan-era budget cuts threatened to force CDC staff layoffs, with devastating impact on agency plans and morale. NIH had no coordinated strategy for addressing the new disease, while clinic doctors were literally writing rules as they went along on how to treat the now-renamed "AIDS." Gay aides on Capital Hill tried pressing for increased federal research support. However, NIH representatives and Health and Human Services (HHS) Secretary Margaret Heckler officially assured skeptics that funding for AIDS work was "more than adequate." At various times, budget planners even proposed cuts of 10 percent or more. Meanwhile, between 1983 and 1985, United States AIDS cases jumped from three thousand to sixteen thousand, finally attracting significant national media coverage, especially after announcement of actor Rock Hudson's infection. Though Surgeon General C. Everett Koop began preparing to address the public on the nature and prevention of AIDS, concerned observers detected damning lack of leadership, if not outright sabotage, by the Reagan presidency and federal bureaucracy on research to fight the new fatal illness.¹⁷

With increasing awareness of AIDS, 1980s gay community leaders mobilized resources for both medical and political efforts. Just as feminists had founded the Boston Women's Health Collective, National Women's Health Network, DES Action, and National Breast Cancer Coalition to call attention to women's health, so gay groups created new AIDS organizations. One West Coast group evolved into the San Francisco AIDS Foundation, while New York leaders established Gay Men's Health Crisis, along with the American Foundation for AIDS Research (Amfar).

The most brazen group, ACT-UP (AIDS Coalition to Unleash Power), had been organized in 1987, largely at New York writer/gay activist Larry Kramer's initiative. Members targeted public figures they believed had

expressed insensitive attitudes or failed to show proper commitment to fighting AIDS, from Michael Dukakis and Ed Koch to George Bush and Jesse Helms. Hundreds of ACT-UP supporters took political confrontation to radical heights, designing strategies to draw media attention; most notably disrupting a December, 1989 mass at New York's St. Patrick's Cathedral to condemn church positions on AIDS, condoms, and sex education. Protesters also broke into government hearings, prime-time network newscasts, and political speeches across the country to vent opinions on the AIDS crisis.¹⁸

Behind such public protest, AIDS activists organized special committees to help care for patients, prepare and distribute preventive public health information, and support research on the disease. As advocates educated themselves about medical details, that sense of knowledge helped some approach health experts on an informed footing, winning professional respect for their seriousness. But the late 1980s proved discouraging; while laboratories turned up apparently hopeful clues to disease mechanisms, converting such findings into practical treatments continued to be difficult and slower than even some experts had predicted. Linking this medical impasse to lack of adequate research funding, frustrated activists blamed government apathy for extending the crisis; Kramer called federal efforts to fight AIDS "murderously slow."¹⁹

Advocates complained that once developed, medical treatments took longer than necessary to reach desperate patients, due to dragging government regulatory processes. In addition to familiarizing themselves with medical facts, AIDS groups also started learning how NIH and FDA operated, to challenge those authorities more effectively.²⁰ Incensed with seemingly unconscionable bureaucratic delay in approving new drugs, ACT-UP staged sit-ins at NIH and "die-ins" in front of FDA facilities to dramatize demands.²¹ The call for action on a 1994 World AIDS Day poster ran, "Red ribbons are a nice gesture. It's red tape we won't stand for."²²

FDA drug approval processes had evolved over decades, reflecting various concerns of physicians, pharmaceutical lobbyists, and (infrequently) even the public. Since the 1960s, as the FDA consolidated power and placed highest priority on avoiding thalidomide-style disaster, time elapsing before approval lengthened. Accusing the "snail-like" FDA of having "buried" pharmaceutical companies under "increasingly onerous" and "arbitrar[y]" rules, Tufts analyst Louis Lasagna wrote in 1989, "The FDA prides itself on being the most demanding regulatory agency in the world... remarkably unconcerned about any drug lag...."²³

Standard procedure before the 1980s allowed corporations, doctors, or other sponsors to register Investigational New Drug applications with the

FDA after conducting basic safety studies on animals. The IND then provided go-ahead for three-stage human clinical testing (with continued animal tests): Phase I small-group clinical pharmacology tests designed to identify any negative side effects; Phase II controlled clinical investigations to evaluate effectiveness; and larger-scale Phase III double-blind work with placebo controls. Products passing all three levels were cleared to file a New Drug Application, with one last review of data to gain final market approval.²⁴

But by the late 1980s, AIDS groups such as Treatment Action Group (TAG) and Project Inform subjected established approval procedure to tough new scrutiny. For victims of drastic terminal disease, advocates argued, conventional concerns about side effects and scientifically-measured efficacy were meaningless, while trials comparing new treatments with placebo controls or older drugs inhumanely denied subjects access to promising medicine. While activists fought the system, patients travelled to Mexico to acquire drugs not yet approved in the United States or patronized "black market" clinics which offered a wider range of treatment options than regular doctors.²⁵

Late 1980s FDA operations floundered as staff tried to cope with expanding responsibilities under tight Reagan budgets. But 1987 policy changes moved toward accommodating demands of extremely sick patients; under a "treatment IND," doctors could give victims of "immediately life-threatening disease" potentially beneficial medicines which had not yet passed final investigation. Moreover, while the agency insisted on continued vigilance to block potentially dangerous or fraudulent treatments, it agreed to experiment with allowing some patients to bring from abroad medicines not yet approved in America and letting doctors test old drugs for new uses.²⁶

The 1991 appointment of pediatrician and law professor David Kessler as new FDA commissioner led the agency to acknowledge and deal more explicitly with AIDS groups' pressure, just as Healy's NIH work both reflected and affected the changing political context of breast cancer concern.²⁷ Establishing new relationships with informed activists (among others), Kessler moved FDA toward a new image of responsiveness while maintaining responsibility for public safety. An HHS Committee review encouraged the agency to foster more rapid and "dynamic" approval procedures, and Kessler agreed that in "balanc[ing] the need to make drugs available quickly with the need to ensure that patients do not receive unsafe or ineffective products," FDA could afford to swing toward facilitating access for fatal diseases such as AIDS. For such desperate cases, the FDA soon instituted special accommodations for "accelerated approval";

while officials would still require basic safety tests, agency decisions could come before extensive trials proved effectiveness or without waiting for precise application terms to be refined.²⁸

Largely in response to such internal and external pressure, FDA's average time before deciding to approve or deny new drug applications dropped 42 percent between 1987 and 1992, from thirty-three months to eighteen, the GAO reported. In December, 1995, the FDA proudly pointed to record speed in approving the new protease-inhibiting AIDS drug saquinavir, just over three months from the manufacturer's first submission. In fact, officials announced, all six anti-AIDS drugs approved in the preceding seven years had come through government review in six months or less.²⁹

Early 1990s AIDS activism had not run perfectly smoothly; some advocates expressed resentful sense that public attention had faded away. Critics worried even the gay community was experiencing "compassion fatigue" or "AIDS burnout," while charging leaders let themselves be distracted by other political questions such as repealing the military ban on homosexuals. Nevertheless, AIDS advocates had established their legitimacy, a sense of a right to be involved with policy-making at NIH and FDA, the administration and Congress. In December, 1995, activists gathered at the first White House conference on HIV and AIDS, along with researchers and medical officials, to encourage and pressure Clinton to maintain government's fight against the disease. Meanwhile, the CDC announced AIDS stood as the leading source of fatality for white men twenty-five to forty-four years old, and the third cause for women that age (behind cancer and injury), with 41,930 overall American AIDS deaths reported in 1994.³⁰

Politicizing Numbers, Politicizing Research Money

AIDS and breast cancer advocacy, of course, were not absolutely identical. For example, though women concerned with health issues were able to draw on increased female Congressional representation after 1992, gay groups could not count on having as many "natural" allies come forward in the political establishment. Overall, however, activist development for breast cancer and AIDS displayed significant parallels; in both cases, mobilized organizations transformed a group's specific medical problem into concerns defined as politically crucial. Both AIDS and breast cancer could leave victims feeling powerless, a sense reinforced by consciousness of women's and gays' status as "outsiders." Political activity offered a way to rechannel frustration, away from individual battles against an enemy

inside (disease itself), into organized campaigns challenging stubborn outside forces ("the political establishment," "medical system," or both). Even if policy changes and renewed research funding came too late to bring a particular patient/activist any personal medical help, organizations drew the individual into a broader fight, promising their commitment would broadly benefit entire groups of others, even curing or preventing future disease. Both breast cancer and AIDS activists operated from conviction that previous medical funding and research policy had been systematically biased against investigation of "their" disease. Some almost-moralistic undertones insisted government and medical authorities confess previous "injustices," then to be atoned for by generous new spending.

Similarities between AIDS and breast cancer activism should not be surprising. From the late 1980s on, leaders in the two camps studied each other's work, modelling new efforts in light of what had succeeded for the other cause. Breast cancer advocates adopted tactics initiated by AIDS activists and vice versa,³¹ cooperating where they saw common need for action. For example, members of Women's Health Action and Mobilization (WHAM!), sharing ACT-UP's aggressive political inclination, joined the 1989 St. Patrick's protest against certain Catholic moral precepts. Each movement developed special fund-raising and public awareness events (from breast cancer-benefit fashion shows, to AIDS-benefit theater, music, and art events). Both causes even acquired shorthand symbols of support: red ribbons for AIDS and pink for breast cancer, fashionable accessories among regular Americans and Hollywood celebrities wishing to display political and philosophical solidarity with activists.

In both cases, AIDS and breast cancer activists achieved certain recognition by White House and Congressional politicians, doctors, FDA and NIH officials even as they harshly criticized government and medical authority. As examples, the 1992 International Conference on AIDS offered a forum to representatives of TAG, one of the groups pushing to reform drug approval,³² while health agencies arranged for advocates to participate in grant review and research planning.

To support demands, both AIDS and breast cancer activists relied on figures purporting to demonstrate basic inequities in the medical system, but numbers could be disputed. For example, while many scientists, medical experts, and journals agreed with feminists that gender balance in research should be a source of concern, others disputed that severe bias had been as widespread as critics portrayed. A 1991 NCI study noted, for instance, that women, 35 percent of new lung cancer cases, accounted for 33 percent of subjects in lung cancer clinical trials.³³

AIDS and breast cancer groups also employed numbers for broader

purpose; to emphasize the urgency of increased funding, activists repeatedly stressed how many Americans were threatened by "their" disease. Such statistics could be challenged; especially in early years of AIDS concern, projections of total infection and relative demographic risk varied widely, from conservative to apocalyptic. Breast cancer activists' literature, placards and buttons spread the byword that the disease confronted one in nine American women; one group adopted the slogan "one in nine" as its name.³⁴ While easy to remember and politically powerful, the message could be misleading, since the number only held true given assumptions of an 85-year lifespan for women. Furthermore, rather than striking one in nine at any age, breast cancer in reality exhibited far greater statistical incidence in older women. In projecting younger women as its face, then, the movement tended to distort relative risks. Activists declared, however, "If the disease continues to spiral at the present rate, our daughters and granddaughters will have a one in four chance of... breast cancer."³⁵

Breast cancer activists deserved credit for tangible progress in public awareness, both through the movement's own campaigns and the drive for increased media coverage. By the 1990s, the number of American women having mammograms rose significantly; up to 65 percent of females past age forty had breast exams.³⁶ Earlier diagnoses, combined with better treatment options, were cited as factors in the 4.7 percent decline in breast cancer deaths between 1989 and 1992; fatality for women age thirty to fifty-nine dropped eight or nine percent.³⁷ Clearly, through the mid-1990s, many important questions about breast cancer remained unanswered, especially relating to the exact nature of risk factors such as diet, environment, and genetics. Many doctors testified to need for further investigation; Susan Love stressed the goal of developing practical tests to screen breasts for cancer on a regular basis, analogous to the way Pap smears checked for cervical cancer.³⁸

As activists turned numbers into a political tool to gain clout, they established breast cancer funding as a key vote for politicians to show dedication to women's concern. However, Washington could support only so many key issues, and defining breast cancer as *the* primary principle risked in effect shunting aside other female health problems, arguably at least as serious. Similarly, American women themselves started thinking of breast cancer as their single greatest health danger, overwhelmingly out of proportion to actual risk. One study showed 46 percent of women convinced that breast cancer posed a major threat, though only 4 percent overall were likely to develop it; by contrast, while 36 percent could be expected to face heart disease, a mere 4 percent judged cardiac problems

a serious risk.³⁹ Of course, the very idea of cancer in general had acquired terrible emotional connotations, while some observers contended that breast cancer represented a uniquely terrifying form. Because of the significance attached to breasts in American culture, they argued, the cancer threatened the most vital physical and psychological sense of feminine identity.

Nevertheless, while breast cancer advocates established the issue at the center of women's health politics, drawing cover stories in *Newsweek*, the *New York Times Magazine*, and *Ms.* (among other publications), heart disease remained the primary source of overall female death. Though relatively unnoticed politically, cardiac trouble proved fatal for close to six times more American women than breast cancer. Since the 1950s, Mayo Clinic studies indicated, women's incidence of coronary heart disease rose even as men's rates dropped, while female heart attack fatality passed male death rates. While research had not yet solved many breast cancer questions, risks and treatment of women's heart disease also entailed medical unknowns and issues of gender bias.⁴⁰

Moreover, medical reports emphasized that lung cancer, with increasing incidence and high mortality, actually accounted for more female deaths per year than breast cancer. Comparing 1975–1979 to 1987–1991, lung cancer incidence in women grew 65.3 percent, versus a 2.5 percent rise in men, according to NCI. While smoking had once been predominantly a male habit, discouraged if not forbidden for women, modern social change led female cigarette use to start catching up. Studies since the late 1970s showed teenage girls more likely than boys to experiment with smoking, as an appealing way to control weight or stress; some tobacco company advertising also increasingly targeted young women. Extrapolating from present trends, one PHS official suggested women's cigarette use would pass men's by 2000, reshaping female health risks.⁴¹ While breast cancer medicine offered no miracles by the 1990s, other types such as ovarian cancer also remained notably difficult to detect and colon cancer hard to treat. A 1994 report, "Cancer at the Crossroad," concluded that though the country had invested over \$23 billion on general research in twenty-three years since President Richard Nixon's "War on Cancer," relatively little overall progress had been made on the disease.⁴²

Such facts served as reminders that while activists had won new consideration for the important breast cancer issue, no comparable political clout had been mustered for other serious diseases in women such as lung cancer or heart disease. Activists such as Love dismissed fear that breast cancer might deplete other research, maintaining health should not be a zero-sum game and that funds could easily come out of "useless govern-

ment spending." But while an ideal world might offer ample money to study all disease, 1990s political and financial reality, such as renewed attention to balanced budgeting, brought talk of tough review of scientific and medical spending.⁴³ Nevertheless, through early 1996, breast cancer advocates in Congress had succeeded in largely protecting their gains in funding from the threat of harsh cuts.

Within that political context, those concerned about other diseases felt compelled to try developing new power to keep up with AIDS and breast cancer activism. In 1996, the American Heart Association complained the nation spent \$1,700 in research per heart-disease death, versus \$39,000 per AIDS fatality. AIDS activists insisted the comparison did not hold, since heart research was well-established while AIDS still involved tremendous unknowns, but the Heart Association announced its intent to engage in letter-writing, marches and other attention-getting tactics which had worked for AIDS politics. But at the same time, AIDS and breast cancer activists declared still more ambitious federal funding goals; the National Breast Cancer Coalition directed supporters to ask Clinton and Congress to "invest \$2.6 billion in quality breast cancer research to find a cause and cure, between now and the Year 2000."⁴⁴

Breast cancer and AIDS activism promoted the impression that given past shortfalls in research, any sizable new funding would by definition be money well spent. The politicized drive for specific disease funding sometimes threatened to rush ahead of scientific ideas on how best to use new resources. *Nature* described one version of a 1991 NIH report on planning women's health research as just "a laundry list of needs," calling for "urgent... research" on "every conceivable aspect of a women's life from conception to death" while conspicuously "missing... proposals for scientifically innovative ideas."⁴⁵ In other cases, high-profile disease politics led to some detours around established medical system planning, as with the 1993 special \$210 million appropriation for breast cancer research allocated not to NIH, FDA or NCI, but the Department of Defense.

Though the devastating impact of AIDS and breast cancer made it difficult to challenge the need for progress, some critics did question the merit of skyrocketing funding. Commenting on perceptions of discrimination against women's health, University of Southern California Norris Cancer Center biostatistician Leslie Bernstein said in 1995 that "the academic world... always had funding to research breast cancer. Less has been spent on studying male-only cancers like prostate cancer and testicular cancer..." One policy analyst (and former breast cancer patient) worried that activist politics meant "micromanagement of science that doesn't result in the best spending..." while Georgetown's cancer center head agreed with concern about "advocacy going overboard."⁴⁶

Love classed such opinion as "backlash" from researchers who resented having to accede to new "taxpayer" new power in directing funding; however, some doubts not so easily dismissed came from individuals sympathetic to women's causes. Columnist Anna Quindlen noted in 1993 that when NCI "now spends more for research on breast cancer than for prostate, ovarian, colo-rectal and liver cancers combined," it showed "something wrong... with how survivor advocacy has driven research dollars... a research agenda that relies so heavily on who makes the most noise." Women's health, she said, would be best served by "a big-picture policy in which, without fear or favor, funding decisions are based on what will yield best results..." determined by science rather than politics.⁴⁷

Challenging Research and Testing Procedures

Fundamentally, AIDS and breast cancer activists were challenging and politicizing not only funding, but the structure and scientific values of research itself. Under ongoing criticism that NIH had not effectively mandated gender balance in research pools, 1994 agency changes set new guidelines requiring clinical trials to make "valid analysis" of whether the treatment in question affected women and minorities differently than white males. Some scientists resented the policy as imposition of political correctness which would cause delay and add to research cost; a Johns Hopkins biostatistician called it "very foolish and very harsh law that is not in the public's interest." Similarly, for AIDS, some researchers feared that FDA policy change granting more generous access to experimental drugs actually undermined scientific need to acquire knowledge about new medicines. A 1994 FDA review of accelerated approval showed that after treatments such as DDI and DDC became available, manufacturers never completed follow-up research proving effectiveness. While it was one thing for advocates to win political battles, it remained another matter to convince researchers that resulting policy change did not hurt medical progress.⁴⁸

Some AIDS and breast cancer activism explicitly challenged fundamental scientific method such as randomized research trials comparing new promising treatment against placebos or older drugs. AIDS groups objected that random tests might leave some patients stuck with ineffective medicine; a tombstone-shaped poster at one protest read, "I got the placebo." Some FDA officials and researchers feared such objections might end up undermining necessary studies of new AIDS medicine, if "compassionate" or accelerated approval policy offered patients alternate ac-

cess to experimental drugs without risk of "getting the placebo."⁴⁹ Similarly, some women voiced displeasure with randomized controlled testing, as researcher Ann Oakley found in a British study of whether home visits and other support made pregnant women more comfortable and resulted in healthier babies. Midwives in the study, worrying that mothers who really needed help might end up in the control group, tried to subvert randomizing mechanisms by persuading secretaries or otherwise trying to steer certain subjects into the list assigned home visits.⁵⁰ Though scientists relied on random clinical trials as a vital scientific method for eliminating bias and so yielding objective results, outside observers did not necessarily value the procedure similarly.

In other cases, breast cancer and AIDS patients actually rejected scientific testing procedures. According to a 1995 report, NCI tests of bone marrow transplants as breast cancer treatment had been undercut because women feared they might be randomly placed in control sections receiving less aggressive therapy. When possible, patients simply chose to avoid enrolling in NCI trials, instead just finding providers willing to give them transplants directly. Worrying that failure to recruit enough subjects might make it impossible to conduct valid tests, the NCI project head hoped physicians might "take a stand and not let this stampede to bone marrow transplant continue"; however, women themselves were expressing reluctance to "be a guinea pig."⁵¹ Similarly for AIDS, some observers suggested that patients had become so infuriated with complex eligibility requirements surrounding research projects that they engaged in "rampant 'lying and cheating'" to be accepted into promising studies. In other cases, subjects might drop out of testing if they suspected they had gotten placebos, or else might share medication with others, adjust dosages as they saw fit, or secretly continue alternate types of treatment. According to one analysis, such individuals could "justify non-compliance with protocols" by adopting a "coercion defense"; if society and science refused to recognize their need for medical support and free choice of treatments, patients bore no obligation to comply with the medical system's rules.⁵²

Challenging Scientific Authority

Beyond questions of research funding and testing procedure, some AIDS and breast cancer activists literally confronted researchers whose perspective did not seem politically acceptable; at a 1994 American Association for the Advancement of Science panel, critics who accused NCI, FDA

and the American Cancer Society (ACS) of ignoring links between breast cancer and environmental pollution "exchanged insults with...sceptical scientists."⁵³

Some activists' interpretations directly challenged medical system motives. As *Nature* observed in 1991, women's health advocates often put "faith in the belief that disease can be prevented by appropriate behaviour, implying that the behavioural and social sciences are as important as the traditional biomedical sciences in creating a new research agenda... a view that would predicate a change in... NIH... mission."⁵⁴ Some breast cancer advocates accused the medical establishment of systematically denying any evidence of nutrition and environmental pollution as causal factors. A 1993 *Ms.* article blamed cancellation of an NCI study on whether low-fat diets could lower cancer rates on clinicians "accustomed to having a virtual monopoly on the breast cancer research pie." The author, head of the National Women's Health Network's Breast Cancer Committee, accused doctors of favoring high-tech, high-intervention and high-cost chemical and hormonal cancer treatment; changing diet would not give medical interests dollars or prestige, but [i]magine the profits if half the healthy population were put on yet another drug." Another piece accused NCI and ACS of neglecting evidence linking breast cancer to organochlorine contamination, quoting a University of Illinois environmental medicine professor who called "the cancer establishment... myopically fixated on obsolete blame-the-victim theories." In conspiratorial-sounding language, *Ms.* maintained that "a golden circle of power and money," including "mostly male" medical centers, doctors, drug companies, ACS and NCI, pursued mutually-beneficial political and financial interests while rejecting evidence which threatened their control. This inside group could then be defined as the opponent—the *Ms.* cover asked, "Why Did They Dismiss Dietary Fat?"—"they" meaning NCI and other institutions "firmly locked into the myth perpetrated by the modern medical profession" pushing pharmaceutical interests ahead of lifestyle and environmental health concerns.⁵⁵

Breast cancer and AIDS activists did not hesitate to use political clout to force reconsideration of science which did not suit their convictions. In the 1990s, Long Island women detected what seemed unusual clusters of breast cancer in certain counties and focused on water supply contamination as cause. Examining the data, investigators for New York State found no scientific justification for further pursuit; but the Long Island Breast Cancer Coalition, unsatisfied by that decision, won backing from Senator Alfonse D'Amato to push for re-opening the question. At a public hearing convened by the Center for Disease Control (CDC), Long

Island activists expressed conviction that pesticides and toxic waste lay behind area breast cancers. The CDC subsequently found no scientific basis for concern about Long Island breast cancer and pollution, yet thanks to political mobilization, Congress allocated money to undertake a special investigation anyway.⁵⁶

In other cases, advocates challenged what authorities said were rational decisions to end ineffective research. When NIH judged in 1994 that alternate proposals and programs for other cities should supersede New York clinical AIDS trials, Gotham's politicians joined activists and patients in protest. While agency officials insisted the move would shift funding from "mediocre" to "the best science," city doctors maintained that NIH had failed to consider New York's sheer number of AIDS patients and need for fair minority representation in trials. TAG activists called for an independent review of why competing programs ranked ahead of New York's.⁵⁷

As further challenge to authority, activists and medical allies disputed official rulings on the value of ideologically-appealing drugs. In the early 1990s, after the Kenya Medical Research Institute claimed impressive improvement in AIDS patients' immune resistance and health status after oral alpha interferon treatment, some African-American activists became vocal proponents. Though NIH found no scientific support, segments of the African-American community alleged that racism kept federal authorities and the medical system from acknowledging value in African-derived therapy. Members of the National Medical Association, a black doctors' professional group, expressed confidence in oral alpha interferon's efficacy. Surrounded by controversy, NIH re-opened the question in 1992, moving to undertake clinical trials re-assessing the Kenyan treatment.⁵⁸ Of course, desperate patients in earlier instances had maintained faith in certain medical options even after expert assessment judged them worthless, as illustrated in the case of Laetrile. By the 1990s, however, the impressive political clout of breast cancer and AIDS could actually persuade government authorities to re-open investigations after first rulings did not serve advocates' political pleasure. Activist pressure even helped win 1996 FDA approval for highly experimental transplant of baboon bone-marrow into an AIDS patient, even as experts warned such animal-to-man tissue grafts risked medical nightmare by facilitating spread of new viruses. One researcher figured officials only agreed since the test was expected almost definitely to fail, with the human system rejecting baboon material,⁵⁹ but the incident highlighted how scientific considerations had become negotiable within the highly charged political environment of AIDS.

Questioning of medical authority on breast cancer and AIDS came in a period which also showed broader American skepticism of conventional medicine. According to one 1990 report, over 33 percent of AIDS patients used unorthodox therapies such as acupuncture, imagery, megavitamin doses, and unapproved medicine. A more general 1993 study correspondingly shocked the medical profession, showing one-third of adults supplementing visits to regular physicians with chiropractic care, relaxation technique and other alternative treatments for physical pain (back and headaches) and other problems (anxiety, depression, and insomnia). Such therapy found a home within mainstream health institutions; by end of 1995, the relatively new NIH Office of Alternative Medicine had given out almost \$8 million in research support, while Harvard, UCLA, and thirty other medical schools offered classes on unconventional treatments. Alternative medicine's gains came with help from political friends such as Senator Harkin (vitaly positioned as chair of the Senate subcommittee with oversight for health, interested himself in bee-sting therapy), succeeding despite harsh criticism from some doctors, researchers, and agency insiders. In 1994, Harkin publicly battled Dr. Joseph Jacobs, former head of the Alternative Medicine office, who charged the senator with "professionally insulting" attempts "to politically intimidate" officials. Brandishing his role as unconventional therapy's political champion, Harkin accused Jacobs of not being properly committed to honest studies of alternate medicine. But for many scientists, the new NIH office and medical courses confirmed fear that non-scientific work was gaining a foothold in respectable institutions, violating the ultimate divide between objectivity and quackery.⁶⁰

For some feminists by the 1990s, the issue of what justified scientific authority had become a powerful philosophical issue. Critics such as Sandra Harding suggested that by definition, science could not be isolated from its historically male-dominated political and social context, so resulting sexist and racist bias undermined the system's supposed objectivity. Though such feminists maintained their analysis was meant to help improve scientific accuracy, some scientists interpreted it as academic-leftist "hostility," hopelessly misguided attacks out to destroy science.⁶¹

Conclusion

Breast cancer and AIDS activism had generated high political profile in relatively brief time, drawing support from growing organizational power and aggressive strategy. For AIDS and breast cancer patients, frustration

with vicious disease readily translated into protest against government and medical systems; as one woman declared, "Nothing will ever happen to breast cancer unless it is politicized." Activists even influenced public perceptions of risk; though AIDS and breast cancer both undeniably represented terrible problems, their political description as an "epidemic" or "holocaust" which "attacks... brutally and indiscriminately" sometimes threatened to overshadow other serious disease. Convinced that research-establishment bias against women's health and AIDS had shortchanged previous funding, activists harnessed numbers and political power to win significant increases in federal research targeted to "their" diseases.

Both AIDS and breast cancer groups maintained that medical and government narrow-mindedness required them to challenge not just the direction of appropriations, but also established research policies and fundamental scientific values. While scientists considered peer review and controlled testing proven methods for confirming results, critics disdained such rules as bureaucratic nonsense biased to exclude alternate ideas. Even as some researchers complained about endangering the integrity of science, activists took philosophical pride in challenging the system. Advocacy meant defining enemies; unwilling to accept official decisions against politically-appealing treatments, activists turned medical rulings into power games for new battle. By the 1990s, federal officials and doctors had been compelled to address this activist pressure, making some basic change in research procedure, allowing interest groups more chances to comment on policy, and even re-opening decisions which had displeased activists.

While breast cancer and AIDS groups were not the first American organizations to fight for specific medical causes and research money, the 1980s-1990s activism was unique in two respects. First, as those organizations gained political power, they reached for unprecedented influence on government agencies, demanding a voice in distributing research funds, changing policy, and setting research agendas. While in earlier decades the March of Dimes had raised significant sums to fight polio, the group followed mainstream medical opinion on the best direction for using such research funds; by contrast, a 1996 breast cancer petition asked the President and Congress to "mandate that... breast cancer activists help determine how the money gets spent."⁶² Second, breast cancer and AIDS activists went beyond other medical causes in posing broad and direct challenges to scientific authority; again, polio groups had not disputed the objective value of research or fought to reverse specific rulings. Breast cancer and AIDS groups did not deny the ultimate value of medicine itself; in fact, they expressed repeated confidence that with significant

increases in funding and national commitment, researchers would find better treatments, cures, and preventive measures for such terrible diseases. Yet to achieve such gains, activists contended, the medical community needed to reform its entire approach, even re-considering the value of randomized testing and supposedly "objective" results to accommodate sensibilities of patients and politics.

By the mid-1990s, breast cancer and AIDS activists had won significant power, reviewing and planning research along with scientists and officials. How had advocates achieved such change in so short a time? One doctor argued that "liberal" researchers and agencies had been "sympathetic to the plight" of seriously-ill patients and also "easily intimidated."⁶³ While that explanation contained elements of truth, it did not fully reflect the power of AIDS and breast cancer activists in taking research to newly politicized heights. In part, these activists may have gained new influence in setting policy precisely because they were able to rally political clout behind such fundamental challenges to scientific method and federal authority. Smaller demands would not have attracted enough public attention to gain political credibility for winning major policy-making concessions, but activists' philosophical and political attacks on the medical system and government agencies resonated with many Americans' broader doubts about authority in the 1980s and 1990s. The activists' critiques alienated some scientists, who resisted what seemed unjustified interference by non-experts who failed to appreciate the value of objective method. But increasing numbers of researchers found some truth in activists' arguments about previous bias in the medical system, leading some doctors, agency officials and politicians alike to decide they could accommodate at least some demands of AIDS and breast cancer groups. By pressing their philosophical and political challenges to scientific and federal authority, AIDS and breast cancer groups won new policy-making authority themselves.

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Notes

1. Figures from the National Cancer Institute and the American Foundation for AIDS Research.

2. Richard A. Rettig, *Cancer Crusade: The Story of the National Cancer Act of 1971* (Princeton, NJ, 1977); James T. Patterson, *The Dread Disease: Cancer and Modern American Culture* (Cambridge, Mass., 1987); and Robert Proctor, *Cancer Wars: How Politics Shapes What We Know and Don't Know About Cancer* (New York, 1995). For a broader look, see Stephen P. Strickland, *Politics, Science, and Dread Disease: A Short History of*

United States Medical Research Policy (Cambridge, Mass., 1972); and Victoria A. Harden, *Inventing the NIH: Federal Biomedical Policy, 1887-1937* (Baltimore, 1986).

3. Susan M. Love with Karen Lindsey, *Dr. Susan Love's Breast Book* (Reading, Mass., 1995), 525; and Robert M. Wachter, "AIDS, Activism, and the Politics of Health," *The New England Journal of Medicine* 326, no. 2, January 9, 1992: 129.

4. The Boston Women's Health Book Collective, *The New Our Bodies, Ourselves: A Book By and For Women* (New York, 1984); and Dana M. Gallagher and Gary A. Richwald, "Feminism and Regulation Collide: The Food and Drug Administration's Approval of the Cervical Cap," *Women and Health* 15.2 (1989): 87-97. See also Barbara Beckwith, "Boston Women's Health Book Collective: Women Empowering Women," *Women and Health* 10 (Spring 1985): 1-7.

5. On DES, see Diana Dutton, *Worse Than the Disease* (Cambridge, 1988); for the Dalkon Shield, Morton Mintz, *At Any Cost* (New York, 1985). For detail on DES development and science issues, see Alan I. Marcus, *Cancer from Beef: DES, Federal Food Regulation, and Consumer Confidence* (Baltimore, 1994.)

6. Sue Rosser, *Women's Health—Missing from U.S. Medicine* (Bloomington, Ind., 1994); Eileen Nechas and Denise Foley, *Unequal Treatment* (New York, 1994); Kathryn Graff Low et al., "Women Participants in Research: Assessing Progress," *Women and Health* 22.1 (1994): 79-98; Joseph Palca, "Women Left Out at NIH," *Science* 248, June 29, 1990: 1601; and "Is There Still Too Much Extrapolation From Data on Middle-aged White Men?" *JAMA* 263, no. 8, February 23, 1990: 1049-1050. See also Michelle Oberman, "Real and Perceived Legal Barriers to the Inclusion of Women in Clinical Trials," in *Reframing Women's Health*, ed. Alice Dan (Thousand Oaks, Cal., 1994), 266-275.

7. Carol Miller, "Women's Health: A Focus for the 1990s," *Bioscience* 40, no. 11, Dec. 1990: 817; Joseph Palca, "Women Left Out at NIH," and "NIH Adjusts Attitudes Toward Women," *Science* 249, September 21, 1990: 1374. During roughly the same period, the U.S. Public Health Service also created a new Office on Women's Health.

8. "Is There Still Too Much Extrapolation From Data on Middle-aged White Men?" See also Paul Cotton, "Example Abound of Gaps in Medical Knowledge Because of Groups Excluded From Scientific Study," *JAMA* 263, no. 8, February 23, 1990: 1051-1052; and Marcia Angell, "Caring for Women's Health—What is the Problem?" *The New England Journal of Medicine* 329, no. 4, July 22, 1993: 271-272.

9. Kathryn Graff Low et al., "Women Participants in Research: Assessing Progress," *Women and Health* 22.1 (1994): 79-98.

10. Paul Cotton, "Women's Health Initiative Leads Way as Research Begins to Fill Gender Gaps," *JAMA* 267, no. 4, January 22/29, 1992: 469; and "NIH Overwhelmed by Response to Women's Health Initiative," *Science* 252, May 10, 1991: 767.

11. *Ibid.*

12. Ruth Kirschstein, "From the NIH: Largest US Clinical Trial Ever Gets Under Way," *JAMA* 270, no. 13, October 6, 1993: 1521; Joseph Palca, "NIH Unveils Plan for Women's Health Project," *Science* 254, November 8, 1991: 792; Paul Cotton, "Women's Health Initiative Leads Way as Research Begins to Fill Gender Gaps," Committee to Review the NIH Women's Health Initiative, Institute of Medicine, *An Assessment of the NIH's Women's Health Initiative* (Washington, D.C., 1993), 90; and David Wheeler, "Women's Health Study Under Fire," *The Chronicle of Higher Education*, November 10, 1993: A9 and A11.

13. Susan M. Love with Karen Lindsey, *Dr. Susan Love's Breast Book*, 518.

14. Cokie Roberts, "One Woman in Nine," *The Washington Post*, February 23, 1992: A19.

15. Christine Gorman, "Breast-Cancer Politics," *Time*, November 1, 1993: 74.; and Laura Bell, "Breast Cancer Research Boom," *Chicago Tribune*, August 27, 1995, 6:8.

16. Susan Ferraro, "The Anguished Politics of Breast Cancer," *The New York Times Magazine*, August 15, 1993: 24-27+; and Gina Kolata, "Weighing Spending on Breast Cancer," *New York Times*, October 20, 1993: C14.

17. Randy Shilts, *And the Band Played On* (New York, 1988); and Sandra Panem, *AIDS*

Bureaucracy (Cambridge, Mass., 1988).

18. Larry Kramer, "The Plague Years," in *The AIDS Reader*, ed. Nancy McKenzie (New York, 1991), 113-121; Russell Miller, "Act UP Hits the Road," *New York Journal*, September 2, 1991; Eloise Salholz, "Acting Up to Fight AIDS," *Newsweek*, June 6, 1988: 42; and Paul Taylor, "AIDS Guerrillas," *New York Magazine*, November 12, 1990: 65-73. See also Josh Gamson, "Silence, Death, and the Invisible Enemy," *Social Problems* 36 (October 1989): 351-367.

19. Paul Taylor, "AIDS Guerrillas."

20. For more, see Harold Edgar and David J. Rothman, "New Rules for New Drugs: The Challenge of AIDS to the Regulatory Process," in *A Disease of Society*, eds. Dorothy Nelkin (Cambridge, 1991), 84-115.

21. "Protesters Ask for More," *Nature* 345, May 31, 1990: 376. Nor did controversy necessarily end once drugs passed FDA requirements; manufacturers as well as government officials became targets of protest. In the late 1980s, ACT-UP attacked pharmaceutical giant Burroughs Wellcome for reputed price-gouging on its anti-AIDS medication AZT, a year's worth of which was priced at \$10,000 in its appearance on the market. Complaining that the drug company was taking profit margins allegedly approaching 80 percent, ACT-UP mounted protests at the firm's headquarters and the New York Stock Exchange, literally dragging floor trading to a halt. While the company insisted that outsiders failed to appreciate the enormous start-up cost of developing such new drugs, it nonetheless cut AZT's selling price roughly 33 percent over the next few years.

22. Stuart Elliott, "Advertising," *New York Times*, December 1, 1994: C11. Ironically, another slogan, "If a murderer kills you, it's homicide... If the FDA kills you, it's just being cautious," came from the opposite end of the political spectrum, an advertisement placed by a conservative anti-regulation foundation. Leon Jaroff, "The Commish Under Fire," *Time*, January 8, 1996: 60. While AIDS activists attacked the FDA's purported slowness in approval from the perspective of dying patients, business groups and conservatives led by House Speaker Newt Gingrich charged the FDA with committing bureaucratic evil through the complexity of its regulatory requirements. Philip J. Hilts, "FDA Becomes Target of Empowered Groups," *New York Times*, February 12, 1995: 1:12; and Connie Mack, "Lift the FDA Roadblock on Experimental Drugs," *New York Times*, February 19, 1995, 4:12.

23. Paul J. Quirk, "Food and Drug Administration," in *The Politics of Regulation*, ed. James Q. Wilson (New York, 1990), 191-235; Peter Temin, *Taking Your Medicine: Drug Regulation in the United States* (Cambridge, Mass., 1980); and Louis Lasagna, "Congress, the FDA, and New Drug Development: Before and After 1962," *Perspectives in Biology and Medicine* 32 (Spring 1989): 322-343. See also James Harvey Young, "Drugs and the 1906 Law"; David Cavers, "The Evolution of the Contemporary System of Drug Regulation Under the 1938 Act"; and Louis Lasagna, "1938-1968: The FDA, the Drug Industry, The Medical Profession, and the Public," all in *Safeguarding the Public: Historical Aspects of Medicinal Drug Control*, ed. John B. Blake (Baltimore, 1970).

24. David A. Kessler, "The Regulation of Investigational Drugs," *The New England Journal of Medicine* 320, no. 5, February 2, 1989: 281-288.

25. Michael Specter, "A Clash of Caution and Urgency," *Washington Post*, October 26, 1987: A15; Martin Delaney, "Patient Access to Experimental Therapy," *JAMA* 261, no. 16, April 28, 1989: 2444, 2447; and Bruce Nussbaum, *Good Intentions: How Big Business and the Medical Establishment are Corrupting the Fight Against AIDS* (New York, 1990).

26. John Iglehart, "The Food and Drug Administration and Its Problems," *The New England Journal of Medicine* 325, no. 3, July 18, 1991, 217-220; and David A. Kessler, "The Regulation of Investigational Drugs."

27. Similarly, in 1995, NCI acquired a new director, Richard Klausner, with an explicit mission, apparently endorsed by NIH, to cut through bureaucracy and so revitalize the agency. Gina Kolata, "New Administrator is 'Not an Administrator,'" *New York Times*, December 12, 1995: B5, B9.

28. John Iglehart, "The Food and Drug Administration and Its Problems;" David A.

Kessler, "The Regulation of Investigational Drugs," 286; "Snipping Away at the Red Tape on Drugs," *U.S. News & World Report*, November 20, 1995: 37; and Philip J. Hiltz, "FDA Approves a New Drug to Attack the AIDS Virus," *New York Times*, December 8, 1995: A9.

29. "Snipping Away at the Red Tape on Drugs;" and Philip J. Hiltz, "FDA Approves a New Drug to Attack the AIDS Virus." In 1996, however, the FDA faced new challenge with Senate and House moves to force further acceleration in agency procedure. Proposed bills spoke about requiring a four-month deadline for action on drugs to fight life-threatening disease and six months for all other applications; FDA failure to meet such time limits would give an automatic go-ahead to the medicine in question for the United States as long as European or British authority had already approved it. The drive for such legislation drew heavily on pharmaceutical business interests; in hearings, Senator Dan Coats accused the FDA of bearing an "approval bias against companies." Denying such prejudice, Kessler warned that such strict deadlines would lead to a drastic Thalidomide-style mistake one day; but House interests talked about going further, allowing some privatization of the drug review process. ABC Nightly News, February 27, 1996.

30. Frank Rich, "Mary Fisher Now," *New York Times*, May 5, 1995: A17; Patrick Rogers, "Surviving the Second Wave," *Newsweek*, September 19, 1994: 50-51; John Carey, "What Happened to the War on AIDS?" *Business Week*, July 2, 1994: 34; David Dunlap, "A Plea to Clinton to Lead US Efforts Against AIDS," *New York Times*, December 7, 1995: A14; and Philip J. Hiltz, "AIDS Death Rate Rising in 25-44 Age Group," *New York Times*, February 16, 1996: A10.

31. J. Gross, "Turning Disease into Political Cause: First AIDS, and Now Breast Cancer," *New York Times*, January 7, 1991: A12.

32. Phyllida Brown, "Activists Home in on Basic Research," *New Scientist*, July 18, 1992: 10.

33. *Science* 251, January 11, 1991: 159.

34. In 1994, over 182,000 American women faced diagnosis of breast cancer, while about 46,000 die from breast cancer per year. The figure "one in nine" was used most commonly in popular discussions, though some breast cancer observers talked about "one in eight" or "one in ten."

35. February, 1996 fundraising letter from the National Breast Cancer Coalition.

36. Complicating the efforts to establish the importance of regular mammograms firmly in women's minds, however, medical organizations and doctors disagreed about the best age to start testing. Claudia Wallis, "A Puzzling Plague," *Time*, January 14, 1991: 48-52.

37. Philip J. Hiltz, "U.S. Breast Cancer Deaths Fell Nearly 5 Percent in Three Years," *New York Times*, January 13, 1995: A17. Screening also complicated scientific questions, since new microscopic and molecular diagnostic techniques permitted researchers to find tiny cancer cell clusters, which some researchers suggested might carry a different meaning than full cancer, proving fundamentally harmless. Autopsies done on females age forty to fifty detected tiny breast tumors in 39 percent, "so quiescent [that]... had they been detected while the woman was alive, they would have been labeled as breast cancer" though not fitting the popular image of cancer as a rapidly spreading mass. Researchers expressed concern that as ability to detect smaller tumors increased, practitioners would face the challenge of deciding how aggressively to treat spots which might or might not turn deadly. Gina Kolata, "New Ability to Find Earliest Cancers: A Mixed Blessing," *New York Times*, November 8, 1994: B5, B8.

38. "Confronting Breast Cancer: An Interview with Susan Love," *Technology Review* (May/June 1993): 4748.

39. Jane Brody, "Personal Health," *The New York Times*, March 8, 1995: B6.

40. From the late 1980s on, a number of medical studies found evidence of gender differentials in diagnosis and treatment of heart disease; in general, men complaining of angina or with potentially troublesome indicators were referred for further testing and surgery earlier and more frequently than women with similar or worse conditions. John Z. Ayanian and Arnold M. Epstein, "Differences in the Use of Procedures Between Women

and Men Hospitalized for Coronary Heart Disease," *The New England Journal of Medicine* 325, no. 4, July 25, 1991: 221-225; Marsha Goldsmith, "Heart Research Efforts Aim at Fairness to Women in Terms of Causes, Care of Cardiac Disorders," *JAMA* 264, no. 4, December 26, 1990: 3112-3113; Jonathan Tobin et al., "Sex Bias in Considering Coronary Bypass Surgery," *Annals of Internal Medicine* 107 (1987): 19-25; and Richard M. Streigart et al., "Sex Differences in the Management of Coronary Artery Disease," *The New England Journal of Medicine* 325, no. 4, July 25, 1991: 226-230.

41. Jane Brody, "Cancer Cases Are Up, But the Future Isn't Bleak," *New York Times*, February 1, 1995: B6; Ingrid Waldron, Diane Lye, and Anastasia Brandon, "Gender Differences in Teenage Smoking," *Women and Health* 17.2 (1991): 65-87; and James O. Mason, "A National Agenda for Women's Health," *JAMA* 267, no. 4, January 22/29, 1992: 482.

42. Susan Jenks, "Cancer Experts Set Research Agenda for Women's Health in the 1990s," *Journal of the National Cancer Institute* 83, no. 20, October 16, 1991: 1443-1444; and "Cancer War Has Stalled, A Panel Says," *New York Times*, September 30, 1994: A11. Among other suggestions, the reviewers advocated creating a cabinet-level cancer-coordinating position, investing at least \$60 million yearly to translate scientific advances into clinical testing, and terminating government support for tobacco production and sale. See also Daryl Chubin, "Research Missions and the Public: Over-Selling and Buying the U.S. War on Cancer," *Citizen Participation in Science Policy*, ed. James C. Petersen (Amherst, Mass., 1984): 109-129.

43. Susan M. Love with Karen Lindsey, *Dr. Susan Love's Breast Book*, 523-524; "Should the Labs Get Hit?" *U.S. News & World Report* November 6, 1995: 83; and Robert Pear, "For Health Agency, A Fiscal Wake-Up Call," *New York Times*, February 20, 1995: A6.

44. ABC Nightly News, February 27, 1996; and February, 1996 fundraising letter from the National Breast Cancer Coalition.

45. Barbara J. Culliton, "NIH Push for Women's Health," *Nature* 353, October 3, 1991: 383.

46. Monika Guttman, "Chasing Breast Cancer," *USA Weekend*, January 13-15, 1995: 24; and Gina Kolata, "Weighing Spending on Breast Cancer." Similarly, regarding AIDS, two Ohio State University doctors wrote *The New England Journal of Medicine* in 1988 to "question the wisdom of allowing its dramatic nature and the public outcry it generates to dictate public policy in health care funding...." Noting that annual American suicides exceeded the 1988 total of people with AIDS, they called it "unreasonable" for the Alcohol, Drug Abuse, and Mental Health Administration to devote 22 percent of total funds to AIDS-related investigations. Such an emphasis, they worried, might draw researchers away from other vital areas of study or induce some to alter projects to include AIDS patients to win grants. Steven C. Dilsaver and Jeffrey A. Coffman, "Effect of Generous Funding for AIDS Research on General Biomedical Research," *The New England Journal of Medicine* 318, no. 16, April 21, 1988: 1071-1072.

47. Susan M. Love with Karen Lindsey, *Dr. Susan Love's Breast Book*, 523-524; and Anna Quindlen, "Competitive Cancer," *New York Times*, October 31, 1993, 4:17.

48. Stephen Burd, "NIH Issues Rules Requiring Women and Minorities in Clinical Trials," *The Chronicle of Higher Education*, April 6, 1994: A50; and Gina Kolata, "FDA Debate on Speedy Access to AIDS Drugs is Reopening," *New York Times*, September 12, 1994: A13.

49. Harold Edgar and David J. Rothman, "New Rules for New Drugs: The Challenge of AIDS to the Regulatory Process," in *A Disease of Society*, eds. Dorothy Nelkin et al. (Cambridge, 1991), 97; and Ellen Cooper, "Controlled Clinical Trials of AIDS Drugs: The Best Hope," *JAMA* 261, no. 16, April 28, 1989: 2445. Advocates maintained that enough people with AIDS would still sign up for trials, either out of "simple altruism" or to receive "free medical care" and "remain in line for future studies." Moreover, one activist wrote in *JAMA* any policy limiting access to new medicine to impel enough subjects to enter testing would seem like "morally offensive" blackmail to AIDS patients, even if researchers emphasized that such tests were crucial to the noble goal of assuring scientific progress.

Martin Delaney, "Patient Access to Experimental Therapy."

50. Ann Oakley, "Who's Afraid of the Randomized Controlled Trial? Some Dilemmas of the Scientific Method and 'Good' Research Practice," *Women and Health* 15.4 (1989): 25-53.

51. Gina Kolata, "Women Rejecting Trials for Testing A Cancer Therapy," *New York Times*, February 15, 1995: A1 and B7; Kara Smigel, "Women Flock to ABMT for Breast Cancer Without Final Proof," *Journal of the National Cancer Institute* 87, no. 13, July 5, 1995: 952-955; and James Mathews, "NCI Survey Explores the MD's Perspective on ABMT Trials," *Journal of the National Cancer Institute* 87, no. 20, October 18, 1995: 1510-1511. Some medical experts indicated that the cure rate for all forms of life-endangering cancers might improve to as much as 75 percent within ten years, but such promise was endangered because just two to three percent of adult cancer patients participated in clinical testing to help investigate and establish better treatment. Jane Brody, "Personal Health," *New York Times*, November 16, 1994: B8. Brody noted that low enrollment could also be traced to doctors who discouraged patients from joining trials (out of fear of complicated regulations and loss of control over the case), as well as practical problems for potential subjects (lack of transportation or child care, for example.)

52. John D. Arras, "Noncompliance in AIDS Research," *Hastings Center Report*, September/October 1990: 24-32.

53. "Conflict Grows Over Breast Cancer Strategy," *Nature* 368, March 3, 1994: 7.

54. Barbara J. Culliton, "NIH Push for Women's Health."

55. Susan Rennie, "Breast Cancer Prevention: Diet Vs. Drugs," *Ms.*, May/June, 1993: 39-40, 42; Liane Clorfene-Casten, "The Environmental Link to Breast Cancer," *Ms.*, May/June, 1993: 54; and Liane Clorfene-Casten, "Inside The Cancer Establishment," *Ms.*, May/June, 1993: 57.

56. Susan Ferraro, "The Anguished Politics of Breast Cancer," 62; and Liane Clorfene-Casten, "The Environmental Link to Breast Cancer," 52-56.

57. Felicia R. Lee, "U.S. Cuts AIDS Research Grants in New York City," *New York Times*, November 8, 1994: A1, B10.

58. Susan Katz Miller, "Faith in 'False Cure' Leads to Renewed Trials," *New Scientist*, November 7, 1992: 7.

59. Christine Gorman, "Are Animal Organs Safe for People," *Time*, January 15, 1996: 58-59.

60. Roger Hand, "Alternative Therapies Used by Patients With AIDS," *The New England Journal of Medicine* 320, no. 10, March 9, 1990; David M. Eisenberg et al., "Unconventional Medicine in the United States," *The New England Journal of Medicine* 328, no. 4, January 28, 1993: 246-252; Robin Wilson, "Unconventional Cures," *The Chronicle of Higher Education*, January 12, 1996: A15-A16; and Tom Carney, "Politics, Science Colliding in Feud," *Des Moines Register*, December 4, 1994: 1B and 3B.

61. See Sandra Harding, *The Science Question in Feminism* (Ithaca, NY, 1986); and Paul R. Gross and Norman Levitt, *Higher Superstition: The Academic Left and Its Quarrels With Science* (Baltimore, 1994). Gross and Levitt also targeted radical environmentalism, Afrocentrism, AIDS activism, animal rights, and postmodern literary theory as sources of "open hostility... toward the assumption, which one might have supposed universal among educated people, that scientific knowledge is reasonably reliable...." For a critique of Gross and Levitt, see Taner Edis and Amy Sue Bix, "Bashing the Science Bashers: Review of Higher Superstition: The Academic Left and Its Quarrels With Science," *Skeptical Inquirer* 19.2 (March/April, 1995): 46-48.

62. February, 1996 fundraising letter from the National Breast Cancer Coalition.

63. Robert M. Wachter, "AIDS, Activism, and the Politics of Health," *The New England Journal of Medicine* 326, no. 2, January 9, 1992: 129.